

# Understanding patient perspectives

Citation for published version (APA):

Thielmann, R. R. L. C. (2023). *Understanding patient perspectives: online access to medical records*. [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20231205rt>

## Document status and date:

Published: 01/01/2023

## DOI:

[10.26481/dis.20231205rt](https://doi.org/10.26481/dis.20231205rt)

## Document Version:

Publisher's PDF, also known as Version of record

## Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

## General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.umlib.nl/taverne-license](http://www.umlib.nl/taverne-license)

## Take down policy

If you believe that this document breaches copyright please contact us at:

[repository@maastrichtuniversity.nl](mailto:repository@maastrichtuniversity.nl)

providing details and we will investigate your claim.

## Impact paragraph

Innovative solutions are required to address the growing pressure on healthcare systems. In line with the paradigm shift towards patient empowerment and patient-centred care, digital care innovations emerge such as patient online access to medical records. This dissertation provides valuable insights into needs, expectations, and perceived effects of patients regarding online access with the aim to evaluate and enhance the potential of online access in improving the quality of care provided to patients.

In this paragraph, the societal impact of the main findings and conclusions of this dissertation will be outlined. This is followed by a description of practical implications for relevant stakeholders. Next, the efforts presently made and yet to be undertaken to disseminate the findings to stakeholders will be outlined. Finally, the scientific impact of the research is summarized.

### Societal impact

The research presented in this dissertation primarily benefits citizens, as the studies aimed to enhance the quality of care provided to patients. While the advantages of online access for healthcare systems at large may not be as significant as initially assumed, this dissertation nevertheless offers valuable recommendations to enhance its potential benefits for individual patients and mitigate potential downsides. Online access to medical records has been described as a double-edged sword which can have both positive and negative impact. This dissertation emphasizes the importance of (re-)designing the system of online access to meet patients' needs and integrate their perspectives.

The key recommendations include providing clear instructions and explanations about online access to patients, prioritizing data privacy and security in development and communication, informing patients about potential effects, and exploring individual patient preferences and skills to support their informed decision-making process regarding the use of online access. If these recommendations are translated into implementation supporting strategies, the findings of this dissertation can thus help patients in making informed decisions about adopting online access. This will increase the likelihood that patients choose an access option for their medical records that aligns with their unique needs, preferences, and abilities, optimally supporting them in their healthcare process. This may also include choosing not to access their medical records at all if this is a patient's preference. Furthermore, better accessibility and comprehensibility of information in medical records is highlighted in this dissertation as an important area for improvement. Offering non-digital options alongside online access is advised to prevent a relative disadvantage for patients with lower digital and health literacy. Implementation of proposed improvements might increase the likelihood that online access will foster patient participation, enhance the patient-provider relationship, and facilitate informed decision-making, regarding for example treatment options. As a result, the research presented in this dissertation may lead to more efficient consultations and healthcare delivery and has the potential to alleviate or at least mitigate the current increase in administrative burden experienced by healthcare workers in general practice due to online access. Ultimately, these improvements enhance the potential of online access for improving the quality of care and can thereby benefit healthcare systems and thus society as a whole.

### Practical implications

In addition to patients, the results of this research bear relevance and practical implications for various other stakeholders. Addressing the implications in this dissertation is a comprehensive and coordinated effort involving healthcare workers in general practice, healthcare organisations, IT companies,

government entities, patient advocacy groups, educational institutions, and intervention planners. Collaboration among all stakeholders might build additional trust and confidence of patients in online access to medical records and facilitate the implementation of proposed improvement measures.

Healthcare workers in general practice are expected to play a crucial role in informing patients about the option of online access, educating them about its potential effects, and addressing data privacy concerns. For patients requiring additional support, healthcare workers may assist in creating accounts or directing them to available resources. However, the responsibility for educating and instructing patients regarding online access should be shared among various stakeholders. Governmental institutions and patient organizations can contribute through educational efforts using, for example, mass media communication channels. IT companies must prioritize data security and privacy in the development of online access platforms, while governments should establish regulations and guidelines related to patient data privacy. Some privacy concerns identified in the interview study (Chapter 2) were based on misconceptions. For example, there was a belief that alongside patients, other healthcare providers than the GP would automatically have access to the data as well. Besides healthcare workers in general practice, healthcare institutions and patient advocacy organizations play an important role in providing accurate information about the privacy safeguards in place for online access, so that misconceptions can be avoided in future.

For organizations and institutions responsible for commissioning and financing IT-related portal improvements, the results emphasize the importance of improving online portals to facilitate easier accessibility of medical records for patients. Further, it will be necessary to design strategies appropriate to modify documentation practices in medical records in order to increase comprehensibility of information for patients. The findings in this dissertation could encourage curriculum developers to integrate the development and promotion of optimal documentation practices that serve both patients and providers in the education of health workers. Additionally, physician education may need more emphasis on effective integration of online access and consultation procedures to support patients in informed decision-making. One possible approach could be physicians employing value clarification exercises with patients. Such exercises aid patients in understanding their personal values and preferences, weighing the pros and cons of different options, clarifying decisional preferences, and ultimately enabling them to have greater control over their healthcare choices. Physician education can equip healthcare professionals with the skills to employ those exercises and support patients in using online access as a tool to make better informed decisions, resulting in potential benefits for both patients and the healthcare system. However, considering general practitioners' concerns and experiences of the implementation of online access increasing their workload, future research has to explore how this can be accomplished without imposing additional burden on them. One potential avenue for addressing this issue could be through the use of online decision aids. These interactive tools, available on the internet, are specifically designed to support individuals in making informed decisions on various health-related aspects of their lives.

The results of this dissertation can inform intervention developers entrusted with the task of designing strategies to support the implementation of online access. They are equipped with the skills to address the most relevant needs identified in this research by selecting appropriate and effective methods and identifying and involving specific stakeholders to carry out measures. By strategically addressing the patient needs uncovered in this dissertation, intervention developers can help to bridge the gap between high patient interest and low user rates and provide support for patients in deciding whether to use online access. Ultimately, this approach can enhance the potential benefits of online access for individual patients and contribute positively to the broader healthcare system.

### **Involving and informing stakeholders**

Efforts were made to involve stakeholders in the research process and inform them about the findings, so they may apply the knowledge gained in the future.

Conclusions and implications from this dissertation highlight the importance of exploring and addressing the perspective of the specific priority population as an important step in the design of public health interventions. The reflection on the project structure in the general discussion of this dissertation underscores the importance of following a sequential order of steps during the design and implementation of such interventions to enhance their effectiveness and efficiency. The limitations resulting from the project's time structure emphasize the importance of exploring perceptions and needs of the involved groups *before* implementing an intervention. This recommendation is particularly relevant to policy research, wherein the national implementation of a policy is frequently beyond the scope of the research project. We communicated those lessons learned to the funders through the project lead in evaluation meetings. We thereby hope to inspire funders and decision-makers involved in current and future public health promotion interventions to prioritize the sequential order of Intervention Mapping, ensuring that needs assessments and the integration of results take place prior to the implementation of a health promotion intervention. By adopting this approach, decision-makers can increase the likelihood of intervention success and make a more significant impact on public health.

Results from this project informed an impact evaluation of online access by being utilized in a social return on investment (SROI) analysis. We provided information on potential costs for patients and healthcare workers, for example the time patients spend on creating an account in the online portal or consulting the general practice with questions. Additionally, we shared information on potential benefits, such as patients' perception of online access reducing the number of consultations or telephone calls with the general practice. SROI analyses help to determine the social value generated by a particular intervention or project in relation to the resources invested. By contributing to this analysis, the research in this dissertation helped to facilitate that resources are effectively utilized for interventions which are impactful and that policies are designed to address societal challenges.

The results of the research presented in this dissertation were furthermore communicated using infographics, which were published biannually on a dedicated program website ([open-eerstelijjn.nl](http://open-eerstelijjn.nl)). Developed collaboratively with researchers from all working packages as well as communication and design specialists, these infographics summarized and compared recent overarching research findings. In the infographics, the findings were presented in a clear and concise manner combining text, numbers, and illustrations. We aimed to thereby make the information easily accessible, understandable, and sharable for a wider audience beyond the science community, e.g., healthcare professionals and patients themselves. As indicated by the results presented in Chapter 3, communicating the potential effects of online access can support the public's ability to make informed decisions regarding their own use of online access. In addition to sharing specific study results, by presenting scientific information in an easily understandable format we aimed to foster a better understanding of the scientific process and methodologies we employed.

Together with a working group, a teaching session was developed and conducted to disseminate the findings among prospective general practitioners and encourage discussions. I used the ADDIE model (Molenda, 2015) as a framework to guide the development process. The model facilitates educational development by providing a structured approach that involves sequential and iterative steps: analysis, design, development, implementation, and evaluation. This systematic framework ensures a

comprehensive and effective development process for educational materials. In preparation for the session, we included specific questions related to digital care tools in an annual survey that assesses the quality of GP education as perceived by resident physicians (AIOS). This approach allowed us to gain a deeper understanding of their educational requirements concerning digital care tools and enabled us to tailor the session's focus accordingly. Approximately half of the respondents indicated that their current education did not adequately address the opportunities and targeted use of patient online access to medical records and digital consultation techniques. Consequently, the findings of the studies presented in this dissertation informed the development of an interactive teaching session. Titled “De Digitale Huisarts” (in English: The Digital General Practitioner), the primary objective of the session was two-fold: First, it aimed to provide resident physicians with knowledge about the existence, application, benefits, and challenges associated with online access and digital communication options in general practice. Second, it aimed to cultivate enthusiasm among participants and encourage them to embrace and explore the potential of these emerging digital care tools. The lesson was initially introduced as part of the annual summer course for Dutch resident physicians in August 2022, with simultaneous sessions held in Eindhoven and Maastricht. Active participation and lively discussions as well as positive evaluation results of the overall course let us perceive that it was well received. Moving forward, the intention of the working group is to integrate the lesson as a permanent component of the course. Regular updates will be made to ensure that it remains up to date with the evolving landscape of and research about digital care developments and continues to provide relevant and valuable insights to participants.

### **Scientific impact**

The recent implementation of online access in general practice across the Netherlands in 2020 has offered the unique opportunity to examine patients' needs, expectations, and experiences during the initial stages of this nation-wide policy rollout. Through this research, substantial contributions have been made to the understanding of patient perspectives regarding online access.

The articles included in this dissertation published to date have been published in peer-reviewed journals, are available as open access, and made a valuable contribution to the existing body of research in this field. Findings were presented at conferences of the Dutch College of General Practitioners (in Dutch: Nederlands Huisartsen Genootschap), the International Conference on Communication in Healthcare (ICCH), and the European Health Psychology Society (EHPS).

The findings have not only addressed existing gaps in the scientific literature but have also led to the formulation of recommendations for future research. Key recommendations for future research in this dissertation are: (1) Investigate how documentation practices in medical records can be changed to serve the needs of both healthcare professionals and patients; (2) Explore how especially patients with limited digital or health literacy can be best supported in accessing and interpreting medical data; (3) Address the role as well as concerns of GP and other health workers in general practice in promoting and facilitating patient online access as well as the role of the government in supporting them; (4) Monitor development of effects with repeated measurements over a longer time period, ideally including the reasons and frequency of patients' online access usage to contextualize findings; and (5) Explore key conditions in healthcare procedures and patient-provider communication dynamics that create an enabling environment for online access to effectively contribute to patient empowerment.